Hole, B., Hemmelgarn, B., Brown, E., Brown, M., McCulloch, M. I., Zuniga, C., Andreoli, S. P., Blake, P. G., Couchoud, C., Cueto-Manzano, A., Dreyer, G., Garcia, G. G., Jager, K. J., McKnight, M., Morton, R. L., Murtagh, F., Naicker, S., Obrador, G., Perl, J., ... Caskey, F. J. (2020). Supportive care for end-stage kidney disease: An integral part of kidney services across a range of income settings around the world. *Kidney International Supplements*, *10*(1), e86-e94. https://doi.org/10.1016/j.kisu.2019.11.008

Peer reviewed version

Link to published version (if available):
10.1016/j.kisu.2019.11.008

Supportive care for end-stage kidney disease

An integral part of kidney services across a range of income settings around the world

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The views expressed in this commentary are solely the responsibility of the authors and they do not necessarily reflect the views, decisions, or policies of the institutions with which they are affiliated.

Number of words: abstract - 173, manuscript - 3901 (excluding title page, disclosure, acknowledgments, references, tables, figure legends)

Short title: Supportive care for ESKD

Abstract

A key component of treatment for all people with advanced kidney disease is supportive care, which aims to improve quality of life and can be provided alongside therapies intended to prolong life, such as dialysis. This paper addresses the key considerations of supportive care as part of integrated end-stage kidney disease care (ESKD), with particular attention paid to programs in low- and middle-income countries. Supportive care should be an integrated component of care for those with advanced chronic kidney disease, those receiving kidney replacement therapy (KRT), and those receiving non-KRT 'conservative care.' Five themes are identified: improving information on prognosis and support, developing context-specific evidence, establishing appropriate metrics for monitoring care, clearly communicating the role of supportive care, and integrating supportive care into existing health care infrastructures. This report explores some general aspects of these five domains, before exploring their consequences in four health care situations/settings – in people approaching ESKD in high-income countries and in low- and middle-income countries, and in people discontinuing KRT in high-income countries and in low- and middle-income countries.

Keywords: end-stage kidney disease, supportive care, palliative care, conservative care

From the perspective of end-stage kidney disease (ESKD), integrated care includes pre-emptive treatment for people with chronic kidney disease (CKD) and those at risk of acute kidney injury (AKI), alongside kidney replacement therapy (KRT, i.e. dialysis or kidney transplantation) and non-KRT 'conservative care.' A key component of treatment for all people with advanced kidney disease is supportive care, which aims to improve quality of life and can be provided alongside therapies intended to prolong life, such as dialysis.[1] This paper addresses the key considerations of supportive care as part of integrated ESKD care. The authors consider supportive care for people of all ages, both those with and approaching ESKD, with special attention to programs in low- and middle-income countries, and emphasize that supportive care should be an integrated part of care for those with advanced CKD, those receiving KRT, and those receiving non-KRT 'conservative care.' The challenges of delivering supportive care as part of cost-effective, integrated kidney care will vary according to disease epidemiology, health care funding and infrastructure, and the cultural and political issues of a country. An action plan to support the optimal delivery of supportive care across a range of health care and income settings is outlined in Harris et al.[2] This article adds granularity to the recommendations by exploring application of the proposed action plan in four settings – people reaching ESKD and people receiving KRT in high-income countries (HIC), and low- and middle-income countries (**Table 1**). This approach has been chosen to highlight the principal gaps, opportunities, and challenges in supportive care delivery worldwide.

Global inequity in access to kidney care

There is substantial global inequity in access to kidney care. In 2010, an estimated 2.62 million people were receiving KRT worldwide,[3] with approximately 93% of these living in high or upper-middle-income countries. This reflects KRT rates in HIC that are 70 times

higher than in low- and lower-middle-income countries.[4] In HIC, the incidence of KRT has risen progressively over the past half century, although conservative care as a treatment alternative for older, multimorbid people has gained acceptance.[5] Meanwhile, it is in low- and lower-middle-income countries, where ESKD is increasing in prevalence, that most of the seven million people die each year as a result of unavailable or severely limited KRT.[3,6] As well as limited funding for the KRT itself, these less affluent nations have health care worker shortages, including both physician and nursing personnel, with nephrologist densities averaging 0.32 per million population (pmp), compared with over 50 pmp in some HIC.[6-8] Similarly, there is a critical lack of access to palliative care, especially for the poor.[9]

Integrated kidney care can incorporate a combination of treatments aimed at preventing future health complications, such as cardiovascular events and ESKD; management of kidney disease, for example KRT; and supportive care. Relative investment in and contribution of the three domains of kidney care are closely linked with the economic setting[10,11] (**Figure 1**[11]). Higher income countries can provide greater access to all three domains, whereas the World Health Organization (WHO) has rated dialysis service development as low priority in low- and lower-middle-income countries where they recommend efforts focused on ESKD prevention.[12,13] There is a clear need to ensure that efforts to define roles and standards of supportive care are individualized to the health economic contexts in which they will be applied.

Supportive care – for people approaching ESKD, on KRT and withdrawing from KRT

Adults and children with advanced CKD and ESKD experience high symptom burden and have complex health and social care needs.[14-16] The definition of supportive care in the setting of kidney disease has been aligned with the WHO's description of palliative care.[1]

Thus defined, supportive care is *"…an approach that improves the quality of life of [people with kidney disease] and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"*.[17] **Figure 2** depicts supportive care integrated into the care of all individuals with kidney disease, including those with and without ESKD, those receiving KRT and conservative care, and those at the end of life. Key components of supportive care include proactive symptom assessment and management, estimation and communication of prognosis, shared decision making, advance care planning, as well as end-of-life and bereavement care.[1] Each of the three elements of integrated kidney care is required to varying degrees by patients at different points in their disease course, with a tendency for supportive care to increase towards the end of life (**Figure 3**).

Whilst the main components of supportive care have been outlined, and the need to integrate them into routine care recognized, no consensus exists as to what constitutes 'optimal' supportive care for patients with CKD and ESKD.[1] Clear definitions of the key components and role of supportive care could facilitate the development of pragmatic minimum standards, matched to local health care systems, culture, and economic settings.[2] Such standards would facilitate the delivery and measurement of supportive care provision, including analysis of cost-effectiveness in different settings, to inform resource distribution and program delivery. Delineation of supportive care would facilitate assessment of its interactions with preventive treatment and as a key component in the management of kidney disease.

Conservative care – for people approaching ESKD not planning to start KRT

Supportive care is the foremost domain of integrated kidney care for individuals receiving conservative care. However, consideration must be given to three distinct groups who receive conservative care, as provision of supportive care differs for each (**Table 2**).[1] Those who elect not to start KRT or who are medically advised not to start KRT based on their individual circumstances are categorized as receiving 'comprehensive conservative care.' Amongst the oldest individuals and those with major comorbidities, a number of observational studies have demonstrated no clear net survival or quality of life benefit from preparing for dialysis compared with having comprehensive conservative care.[18-21] Individuals who start conservative care due to KRT unavailability receive 'choice-restricted conservative care.' Those who reach end-stage without recognition or a diagnosis are categorized as having 'unrecognized ESKD.' Evidence of the effectiveness of conservative care and the experiences of patients in these contexts is needed. In nations that can provide KRT to all individuals who might benefit, comprehensive conservative care is likely to predominate. Individuals in countries that cannot provide universal KRT may elect to receive conservative care, but most are likely to receive choice-restricted conservative care or die with unrecognized ESKD. Access to supportive care is also likely to be highly restricted for these individuals.

Key components of comprehensive conservative care have been defined (**Table 3**).[1] As with KRT, comprehensive conservative care includes all treatment domains: preventive care, 'minimize risk of adverse events;' management of kidney disease, 'interventions to delay progression;' and supportive care. Nonetheless, treatment elements predominantly relate to supportive care, signifying palliative care as an essential component of comprehensive conservative care. Choice-restricted conservative care and unrecognized ESKD are

compatible with provision of both preventive and supportive care, though neither is presumed.

Opportunities and challenges in the delivery of supportive care

Five themes were identified and included in the action plan in Harris et al.:[2] improving information on prognosis and support, developing context-specific evidence, establishing appropriate metrics for monitoring care, clearly communicating the role of supportive care, and integrating supportive care into existing health care infrastructures. Generalizable aspects are outlined below, before exploring their consequences in four contexts – people approaching ESKD in high- and low- and middle-income countries and people discontinuing KRT in high- and low- and middle-income countries (**Table 1**).

Generalizable aspects of the five themes

Improving information on prognosis and support for people with ESKD

In all settings, the patient preference and perspective must be included in provision of supportive care. While in many cultures this will be best achieved through shared decision making with health care professionals trained in effective communication, it must be recognized that there are different approaches to family involvement in decision making and these do not always follow East-West cultural stereotypes.[22] Regardless, improved evidence is needed regarding how best to support people preparing for life and potential or probable death with ESKD. The probability of ESKD, likelihood of transplantation, and projected survival with each treatment are likely to inform initiation decisions. Dealing with uncertainty is challenging and needs support. Further information is also needed on quality of life and death, and patient reported experiences. The consequences of providing intensive supportive care for people with kidney disease are largely unknown. These may involve

physical and mental health, end-of-life care, and survival, as has been demonstrated in other disease settings.[23]

Making available context-specific guidance on supportive care

Guidance on prognosis and supportive care will have greatest influence if it is readily available, understandable, and context-specific or in a form that allows it to be interpreted in a context-specific manner (including for children, etc., as well as across economic settings). Materials must be accessible to relevant parties and relate to realistic, rather than idealized care.

Establishing approaches to evaluation of care access and quality

Collecting data on aspects of supportive care for CKD, KRT, and conservative care would provide an integrated picture of total kidney care. Defining 'optimal' and 'minimum' standards of supportive care is a necessary first step to assessing whether and to what standard it is being delivered. Inclusion of metrics such as patient-reported outcomes and experiences, dialysis withdrawal, and quality of end-of-life care would facilitate evaluation of the experience of living and dying with kidney disease.

Clearly communicating the role of supportive care

Supportive and conservative care must not be perceived as cost-saving alternatives to provision of other aspects of kidney care, such as KRT. Defining the role of each domain of integrated kidney care emphasizes the eligibility for supportive care of all individuals, including those receiving KRT. Nomenclature may need to be flexible for communication in different cultures and dialects. Rigor is needed, however, to prevent confusion between

conservative care – provided only to those not receiving KRT, and supportive care – beneficial to all people with advanced kidney disease.

Integrating supportive care with existing health care supply chains

Effective and efficient supportive care requires integration with existing infrastructures. Increasing levels of multimorbidity mean that most people with advanced kidney disease will be living with comorbidity.[24] Further, the supportive care needs of people with kidney disease are likely to overlap with those with other life-limiting conditions. Exchange of learning between specialists in kidney disease and experts in multimorbidity and palliative care may be valuable. By defining preventive, kidney, and supportive aspects of kidney management, health care for people with kidney disease may be rationalized.

Setting A: People reaching ESKD in HIC

This section examines the role of supportive care for individuals starting an ESKD treatment modality where direct costs are paid by the state or an insurer. Supportive care for these individuals has two manifestations. The first is as support during treatment decision-making. The second is the supportive care components of each available treatment package – the nature of which might, in turn, influence which is chosen. Broadly speaking, two groups of people require attention:

- Younger, fitter people likely to live substantially longer with KRT than conservative care, deciding on a long-term treatment strategy combining dialysis modalities and/or transplantation. Although conservative care is exceptional, these people would benefit from supportive care, perhaps most importantly in the form of symptom management and psychological support, during decision making and alongside KRT.
- Typically older, multimorbid people for whom the survival benefits of KRT are less and might be traded off against the burden of dialysis. Treatment decisions are between dialysis modalities

and comprehensive conservative care, since transplantation is not medically an option. Supportive care available during decision making, as part of comprehensive conservative care or alongside KRT, will benefit these people.

Optimizing communication and maximizing patient participation in decision-making is a top priority for adults on or nearing dialysis, their caregivers, and health care professionals.[25] Shared decision-making is expected in many HIC.[26] Decision-support tools have been developed and more are in development.[27] Prognostic calculators exist, including some that have been validated in external data sets.[28] However, shared decision-making may not always occur in decisions regarding ESKD, where KRT may be given precedence over comprehensive conservative care during decision-making.[27] Meanwhile, unsystematic efforts to communicate treatment options and aims in advanced kidney disease are reported.[29]

While there are many successful examples of integrated preventive, kidney, and supportive care systems in HIC,[30] barriers and disincentives have the potential to drive under-delivery of supportive care. In some settings this might reflect disproportionate investment in kidney domains of health care (**Figure 1**) which may convey a risk of overtreatment. Even in settings where comprehensive conservative care is well-established, the availability and nature of services can be variable and ill-defined.[31]

Many HIC have registries that are well-placed to appraise delivered care along with dialysis and transplant epidemiology and outcomes. Patient-reported outcome measures have been incorporated into a small number of kidney registry datasets. However, the capture of data for individuals without ESKD is rare, particularly for children. Very little is known about the experiences of people who make an informed decision for comprehensive conservative care.

Recommendations:

- The core components and standards of supportive care, such as symptom control and opportunities for advance care planning, should be defined in a way that permits measurement.
- Chosen standards must be culturally suitable and sensitive. For example, whilst shared decision-making is favored in many western cultures, it may not be a universally appropriate metric as new, non-western countries develop HIC and become able to provide KRT more broadly.
- Information on prognosis and supportive care should be freely available to all relevant parties. Where appropriate, a single repository should be maintained to ensure clarity of communication and prevent duplication of work.
- Registries provide a logical means through which to collect required information. Databases should be expanded to include:
    - All individuals with kidney disease, including:
        - Children
        - Individuals with AKI and CKD
        - Those choosing comprehensive conservative care
    - Quality of life and quality of death
- Robust decision-support tools should be developed to facilitate shared-decision making between KRT and comprehensive conservative care. These should facilitate discussion of prognosis and transplant likelihood.
- Decision-support should be developed for less-well represented populations, including children, and should cover individual and caregiver costs such as travel, loss of employment, etc.

- Nephrology services should interface with primary care, community, and palliative services to ensure that people with kidney disease have access to existing supportive care networks and that their special requirements are met.
- Observational and interventional research is required to understand the system and individual effects and costs of introducing standardized supportive care. Interventions such as decision-aids must be rigorously tested in real-world settings.

Setting B: People reaching ESKD in low- and middle-income countries

This section examines the role of supportive care for individuals residing in countries where the majority of direct treatment costs are not paid by the state. These are individuals who lack private insurance or personal wealth such that they do not have the opportunity to choose KRT or comprehensive conservative care. They may reside in countries where some citizens have access to health care (e.g. state employees) but there is not yet universal health care coverage. For the majority of these individuals, kidney care is unavailable or unaffordable. As a result, they die with undiagnosed ESKD or receive choice-limited conservative care, usually with no access to palliative care.

Individuals and their families in this setting have different supportive care needs from those in more affluent areas. Given low levels of influence over their treatment, supportive care is likely to play a lesser role in decision-support. Nevertheless, a proportion of individuals self-fund a period of KRT. Dialysis may cost 7 to 48 times the average income and can be associated with catastrophic healthcare costs and precipitation of familial poverty.[32,33] For those contemplating self-funding, supporting rational decisions with information regarding the survival and quality of life benefits of KRT alongside financial costs may reduce the need for early KRT-withdrawal and health care-related poverty.

Individuals who cannot access or afford KRT experience high levels of avoidable health related suffering.[34] These individuals need supportive care. Deficiencies of and priorities for palliative care in low-income countries are well-described.[9,34] The essential components of supportive care for people dying with/from non-KRT-treated ESKD need defining but are likely to overlap with familiar palliative care priorities. Where general palliative care services are in place, these may provide models, access to care, and opportunities for establishing costs and effectiveness for those with kidney disease. Supportive care for those receiving choice-restricted conservative care may provide a legitimate alternative for families considering self-funding KRT. Whilst the need for supportive care is clear, it is vitally important that access to palliation does not contribute to under-provision of kidney and preventive domains of care, except where rigorously developed health economic evidence supports this approach.

In resource-limited settings, choice-limited conservative care can be disproportionately provided to older people, children, and those from lower socioeconomic and minority ethnic groups.[35] Capturing data that permit evaluation of inequity could inform policy regarding access to care and equality of services nationally and internationally. This will require metrics that capture delivery of choice-limited conservative care and supportive care. Given the lower penetrance of registries and high levels of undiagnosed ESKD in low- and middle-income countries, routinely collected data are likely to be inadequate.

Recommendations:

- Supportive care should be available to all individuals, including those self-funding KRT and those receiving choice-limited conservative care. Minimum standards of care should be defined.
- Information on prognosis should be accompanied by full details of costing for families contemplating self-funding.
- Alignment with existing networks for the delivery of palliative care is likely to be necessary.
- Studies are needed to identify the effectiveness, costs, and opportunity costs of providing supportive care in low- and middle-income countries.
- Provision of supportive care must not be regarded as an alternative to developing KRT services or investment in preventive care.

Setting C: People receiving KRT in HIC

This section examines the role of supportive care for people on KRT or withdrawing from state/insurer-funded KRT. These individuals are likely to have complex health histories including preventive, kidney, and supportive care, the latter commencing in late stages of CKD and continuing on KRT.

Those stopping KRT do not start conservative care, as such (**Figure 1**), but transition to supportive care becoming the predominant domain. Individuals contemplating KRT cessation are likely to have complex social, psychospiritual, symptom, and informational needs (**Figure 4**). These requirements for supportive care must be met alongside decision-support before and during withdrawal, and if chosen, end-of-life care following discontinuation.

Withdrawal from KRT is reported for up to 30% of people who receive dialysis in HIC.[36] Marked variation in withdrawal rates between countries may reflect differences in culture, practice, and definitions of dialysis withdrawal.[37] A unified definition would enable the generation of higher quality evidence to inform discussions regarding cessation of KRT.[38] Rising levels of comorbidity, including cognitive impairment, are likely to explain at least some of the rise in withdrawal from dialysis.[37] To ensure that individuals' wishes regarding dialysis continuation and withdrawal are respected, these must be discussed and recorded – for example, as part of advance care planning.

Following KRT withdrawal, individuals enter an end-of-life phase and most die within days to weeks.[39] HIC are likely to have established systems for delivery of supportive care, such as palliative care clinicians, hospice care, and access to essential medications. It is important that individuals withdrawing from KRT can access such services. This does not always happen, however, even in HIC in this relatively controlled setting, and death after withdrawal from dialysis does not guarantee exemplary symptom control.[40,41] Given the morbidity and vulnerability of this group, there is an urgent need for metrics and surveillance systems that can quality assure the palliative care received by people at this crucial stage in their treatment. Improved evidence is required regarding medicinal and non-medicinal treatment of the symptoms following withdrawal of KRT.[1]

Recommendations

- Supportive care for all individuals on KRT should include discussion of withdrawal and the opportunity for them to share their values and preferences regarding it. This should include development of advance care plans and directives.

- Access to end-of-life supportive care should be universal for individuals who withdraw from KRT.
- Metrics are required to assess the quality of end-of-life supportive care for individuals who withdraw from KRT. A unified definition of dialysis withdrawal should be operationalized. Data relating to quality of death are needed, but care must be taken not to burden patients and their families during this period.
- Improved evidence is required to facilitate generation of guidelines for management of symptoms experienced by individuals withdrawing from dialysis.

Setting D: People receiving KRT in low- and middle-income countries

This section examines the role of supportive care for individuals on KRT or withdrawing from KRT in low- and middle-income countries. As in HIC, these individuals are likely to have complex health histories including preventive, kidney, and supportive care requirements. Deficiencies in palliative care services are likely to impact upon the availability of support for social, psychospiritual, symptom, and informational needs of individuals receiving KRT in this setting.[34]

Whilst some patients will elect to withdraw from KRT for clinical reasons (comparable with those discussed in Setting C) and many due to financial hardship, an infrequent but important group is those who are compelled to stop for reasons beyond their control. Choice-restricted KRT withdrawal following treatment provider/transplant immune suppression supplier collapse or natural disaster is catastrophic for individuals with ESKD and requires surveillance and reporting at an international level, given the resultant avoidable death and suffering (**Figure 5**).

The treatment priority for individuals mandated to stop due to provider collapse or natural disaster is re-establishment of KRT as quickly as possible. Where impossible, supportive care for those dying from ESKD is required. Individuals in this setting are likely to be substantially younger and less comorbid than those withdrawing from KRT in HIC. Evidence relating to survival and symptom control cannot be extrapolated between these settings.

Recommendations

- Supportive care should be available to all individuals on KRT.
- For individuals who withdraw from KRT, intensive supportive and kidney care should be instituted with efforts made to prolong life, where able.
- Where individuals are mandated to withdraw from KRT due to collapse of a provider or natural disaster, the priority should be the re-establishment of KRT.
- Events where individuals are compelled to withdraw from KRT should be recorded and reported, as should deaths due to dialysis withdrawal.

While the challenges must not be underestimated, it is possible to provide good supportive care in all four of these settings. To illustrate this, four of the co-authors have provided a case study from their recent practice (EB, CZ, MB and MM, respectively) (see **Supplementary Appendix S1**).

Conclusion

Supportive care must be an integral part of the care of people with advanced CKD – those approaching ESKD, those on KRT, and those withdrawing from KRT. To achieve this in all countries of the world, regardless of economic situation, we have identified five themes for work covering patient information provision, evidence-based guidance, processes and metrics

for measurement, clear communication, and alignment with other chronic disease supply chains and infrastructure. Each of these will need tailoring to be context sensitive. There is lots of work to be done, but also lots we can learn from examples of good practice already in place in high- and low- and middle-income countries.

Disclosure

PGB report lecture fees from Baxter. GGG reports grant support from CloudCath and ICON. RLM reports lecture fees from Baxter Healthcare and Amgen One, current grant support from Australian NHMRC TRIP Fellowship and Kidney Health Australia Project Grant, and has grants under negotiation with Australian NHMRC Project Grant (SWIFT). JP reports consulting fees from Baxter and DaVita, lecture frees from Baxter, DaVita, Dialysis Clinic Inc., and Fresenius Medical Care, and grant support from AHRQ Arbor Research. RCW reports grant support from Lotteries Health Research Grant and Baxter Health Care (CEC Research Grant). SJD reports grant support from Baxter CEC and Extramural. All other authors have nothing to disclose. Publication of this article was supported by the International Society of Nephrology.

Acknowledgements

This manuscript emerged as an individual product of the International Society of Nephrology's 2nd Global Kidney Health Summit held in Sharjah, United Arab Emirates in March 2018 and portions of the material in this document have been published in the full report from the Summit (Harris DCH, Davies SJ, Finkelstein FO, et al. Increasing access to integrated ESKD care as part of universal health coverage. *Kidney International* (2019) 95, S1–S33). In addition to the International Society of Nephrology, support of the Summit was provided through unrestricted grants from Baxter and BBraun.

Supplementary Material

Case Studies

Setting A: Comprehensive conservative care in a high-income country

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Setting B: Comprehensive conservative care in a low- or middle-income country

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Setting C: Withdrawing dialysis in a high-income country

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Setting D: Withdrawing KRT in a low- or middle-income country

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Supplementary information is available at *Kidney International's* website.

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Tables

Table 1. Illustrative settings in which supportive care is delivered worldwide

	High-income country	Low- or middle-income country
People reaching ESKD	**Setting A** Supportive care for individuals reaching ESKD where KRT is universally available. (Includes those who choose or are advised not to start KRT).	**Setting B** Supportive care for individuals reaching ESKD where KRT availability is restricted or self-funded. (Includes those who choose, are advised or are obliged not to start KRT).
People receiving KRT	**Setting C** Supportive care for individuals on KRT. (Includes those who choose or are medically advised to withdraw from KRT).	**Setting D** Supportive care for individuals on KRT. (Includes those who choose, are medically advised to, or are obliged to withdraw from KRT).

ESKD, end-stage kidney disease; KRT, kidney replacement therapy (dialysis and kidney transplantation)

Table 2. Definitions of conservative care

Comprehensive conservative care	Conservative care that is chosen or medically advised
Choice restricted conservative care	Conservative care for patient in whom resource constraints prevent or limit access to kidney replacement therapy; therefore, a choice for conservative care cannot be recognized
Unrecognised G5 CKD	CKD is present but has not been recognised or diagnosed; therefore, a choice for conservative care cannot be recognised

CKD, chronic kidney disease; G5, glomerular filtration rate category 5 CKD

Data from Davison SN, et al.[1]

Table 3. Components of comprehensive conservative care

‘Comprehensive conservative care’ is planned holistic patient-centered care for patients with G5 CKD that includes the following:

- Interventions to delay progression of kidney disease and minimize risk of adverse events or complications
- Shared decision making
- Active symptom management
- Detailed communication including advance care planning
- Psychological support
- Social and family support
- Cultural and spiritual domains of care

Comprehensive conservative care does not include dialysis.

CKD, chronic kidney disease; G5, glomerular filtration rate category 5 CKD

Data from Davison SN, et al.[1]

Figure Legends

Figure 1. Components of care received by individuals with kidney disease, conceptualised as preventive (light-blue), management of underlying kidney pathology (mid-yellow) and supportive (dark-green)

Contributions of care components are shown in four hypothetical settings, two high-income, one middle-income, and one low-income: interpretable as countries, regions, or treatment centres. In setting 1, greater total and proportional investment has been made in managing kidney disease (e.g. dialysis services) than in 2, 3, or 4. In 2, greater emphasis on preventive and supportive care is delivered. In 3, preventive treatment and management of kidney disease are funded, but supportive care has not yet been. In 4, preventive treatment represents a greater proportion of service delivered than in settings 1, 2 and 3, though receives less investment in absolute terms. Management of kidney disease (e.g. dialysis) is unavailable in setting 4.

Data from White S, et al.[11]

Figure 2. Supportive care as part of integrated kidney care.

Arrow between conservative care and KRT indicates individuals switching treatment approach. Those with end stage kidney disease who stop KRT receive supportive care at the end of life, not conservative care – which is provided to individuals reaching end-stage as either a chosen or choice-restricted therapy.

CKD, chronic kidney disease; AKI, acute kidney injury; KRT, kidney replacement therapy; Tx, transplantation; HD, hemodialysis; PD, peritoneal dialysis

Figure 3. Hypothetical patient journey showing variation in components of kidney care with disease/time progression

In this example, a patient is already receiving cardiovascular risk management when their CKD is diagnosed. CKD care is then added. At a later date supportive care is added for symptom control. Sometime later they start KRT. Later again, a deterioration triggers deprescribing of preventive care and subsequently a choice to withdraw from dialysis. Supportive care is continuous through CKD, ESKD/KRT, end-of-life and bereavement phases.

Light-blue boxes = preventive care; yellow boxes = kidney care; green boxes = supportive care.

CKD, chronic kidney disease; ESKD, end-stage kidney disease; KRT, kidney replacement therapy

Figure 4. Hypothetical patient journey showing variation in components of kidney care with disease/time progression

In this example, a major health event necessitates changes to all components of kidney care culminating in a discrete shift to a purely supportive approach with the withdrawal of dialysis.

Light-blue boxes = preventive care; yellow boxes = kidney care; green boxes = supportive care.

CKD, chronic kidney disease

Figure 5. Hypothetical patient stories

Patient A starts dialysis for HIV associated nephropathy and dies whilst in receipt of KRT. Patient B follows the same initial trajectory, but treatment provider collapse results in choice-

restricted dialysis withdrawal. Patient B dies prematurely and experiences an abrupt onset of palliative care needs at the point of dialysis discontinuation.

Light-blue boxes = preventive care; yellow boxes = kidney care; green boxes = supportive care.

HIV, human immunodeficiency virus; CKD, chronic kidney disease; ESKD, end stage kidney disease